Consultation on Disability Surveys

Report

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Executive Summary

In general, respondents were very positive about the need for information about all issues identified in the framework found in *In Unison: A Canadian Approach to Disability Issues*. The framework is based on the overarching principle of full citizenship and on the three building blocks required to establish full citizenship—disability supports, employment, and income. These three building blocks, along with full citizenship, were the four themes identified in the consultation questionnaire. Some issues were considered relatively more important than others.

- Information about disability supports and employment was more likely to be identified as a "must have" and to be rated a higher priority than information about income and citizenship.

- The most frequently cited data needs around disability supports were for information about 1) formal and informal supports, 2) unmet needs for supports, and 3) the cost of disability supports.

- Under employment the information most often requested concerned: 1) barriers to employment; 2) the relationship between supports and work; 3) education, training and literacy; 4) movements in and out of the labour force; and 5) youth transitions from school to work.

- Information requirements focussed on 1) financial resources and the cost of disability, 2) income levels and income mobility, and 3) income sources and movement among sources.

- The data needs most often identified for full citizenship were 1) barriers to accessing generic programs and services and the impacts of these barriers, 2) attitudinal barriers to the full participation of persons with disabilities, and 3) housing and transportation.

- More respondents reported that having information about the working-age population in Health and Activity Limitation Survey (HALS) was most important. But having information about children, seniors and the institutional population was equally important to many groups and government departments. The question addressed the issue of how to collect data on children, seniors and residents of institutions – through HALS or through other survey vehicles. Subsequent consultations with Statistics Canada revealed that using other survey vehicles would not be feasible.

- Provincial-level data were necessary for most respondents. A somewhat smaller proportion needed data at the national or regional level. Census metropolitan area-level data were the least required.

- Write-in responses identified additional information needs not covered in the consultation questionnaire, such as transitions from childhood to adulthood.

- Consultation meetings pointed out the need to determine the impact of the physical or mental disability within specific contexts such as work, school, home and community.

- The lack of information about the impact on the family of children with disabilities was identified as a significant data gap along with the need to have more information about medically fragile children and children at risk.

Introduction

This report summarizes the results of a broad consultation undertaken by Income Security and Social Development Studies, Applied Research Branch, Human Resources Development Canada (HRDC) about the Health and Activity Limitation Survey (HALS) to be conducted by Statistics Canada in 2001. The new survey represents one component of a broader disability research agenda. HRDC wanted to ensure that the new survey is based on as much input from the community of users as possible. The consultation process had two components: 1) a written questionnaire and 2) face-to-face cross-country discussions with groups representing persons with disabilities. Statistics Canada was involved in both aspects.

The first consultation component consisted of a self-administered questionnaire and documentation[1] about HALS which was distributed to consumer groups, provinces/territories, other federal departments, researchers, academics and employers (see Appendix A). The material was also available in alternate formats.

The consultation questionnaire was based on the framework developed in *In Unison: A Canadian Approach to Disability Issues*, produced by the Federal/Provincial/Territorial Ministers Responsible for Social Services. The framework document is a blueprint for promoting the integration of persons with disabilities in Canada. 'Full citizenship' is the overarching principle and is defined as "the inclusion of persons with disabilities in all aspects of Canadian society." Three interrelated building blocks to full citizenship were identified: disability supports, employment, and income. 'Disability supports' refers to a range of goods, services and supports tailored to the individual's requirements for daily living. 'Employment' is the basis of financial independence, requires that access to opportunities for education, training and jobs be available. 'Income' recognizes that individuals with disabilities may not be able to support themselves sufficiently or at all and that financial assistance may be necessary.

In the consultation document, questions are posed about each of the three building blocks. In addition, 'full citizenship' is used to assess the barriers and obstacles in other areas such as

[1] The documentation package included copies of the 1991 HALS adult and children's questionnaires, a list of variables, background information on HALS, a conceptual framework for HALS 2001 and a return envelope.

transportation, housing, learning, technology and the voluntary sector, which are also important to HALS data users. Together disability supports, employment, income, and full citizenship comprise the four themes around which the consultation questionnaire is organized.

Respondents were asked about the importance of having information about each of the four themes and about their order of priority. Each theme was then divided into topics and the importance and priority of topics were requested. The objective was to provide information on the relative importance of different subject areas. In addition, there were questions about level of data needed and scope of the survey. Opportunity was provided to write in additional comments and to identify issues not covered in the questionnaire.

The second part of the consultation consisted of meetings with disability groups across the country. HRDC and Statistics Canada met with groups and individual experts in the field. Like the first consultation component, the goal was to determine the most important data needs of users and to allow the community to share their knowledge and experience.

Findings should be interpreted with some caution since not all groups are equally represented among respondents. In addition, while the results revealed that some information needs are more important, the consensus was that having information about all the issues raised was necessary.

HRDC and Statistics Canada are continuing to consult with individuals and groups on an ongoing basis throughout the content development phase of HALS 2001.

Section 1: Consultation Questionnaire

1.1 Methodology

A total of 292 consultation packages were mailed out. Additional requests for packages resulted in about 20 more mail-outs from Human Resources Development Canada (HRDC). Some organizations made copies of the questionnaire and distributed it to others. HRDC has no way of knowing how many additional questionnaires were distributed in this manner. The original deadline to respond was extended to ensure that everyone had sufficient time to reply. One reminder was sent out to the initial mailing list. The total responses numbered 126.[2]

Table 1: Responses by organization

Organizational types	Responses
Consumer groups	28
Provincial/Territorial governments	28
Federal government departments	28
Researchers/Academics	10
Private sector	8
Health regions/Municipalities	5
Others	19
Total	***126***

In cases where more than one questionnaire was sent to an organization, often only one was returned. For example, some federal departments and consumer groups consulted widely within their departments and with their constituencies and then submitted one questionnaire. Due to these factors, calculating a response rate is somewhat problematic. It is estimated to be about 41%.

A broad range of consumer groups responded to the consultation, representing different age groups and disability types. Groups specifically addressing seniors' and children's issues were in the minority, and results should be interpreted with this in mind. Among the twenty-eight federal government responses slightly more than half (54%) were from Human Resources Development

[2] See Appendix A for a list of all respondents including those who completed the questionnaire, those who wrote letters and those who provided written comments.

Canada[3] while the remainder were from other federal departments. Responses were received from nine provinces and two territories. The category of 'others' was a residual category selected by respondents themselves. The analysis looks at the findings from all respondents and then presents results for the largest groups—consumer groups, provincial/territorial governments and federal departments.

1.2 Themes

Respondents were asked about the extent to which information is needed about the four themes. First, respondents were required to rate the degree to which information is needed about each theme and, second, to prioritize the importance of the four themes. A five-point scale was used to measure the extent to which information is needed. The number 1 represented "not needed" and 5 represented a "must have." A 4 or 5 on the scale reflected a positive response.

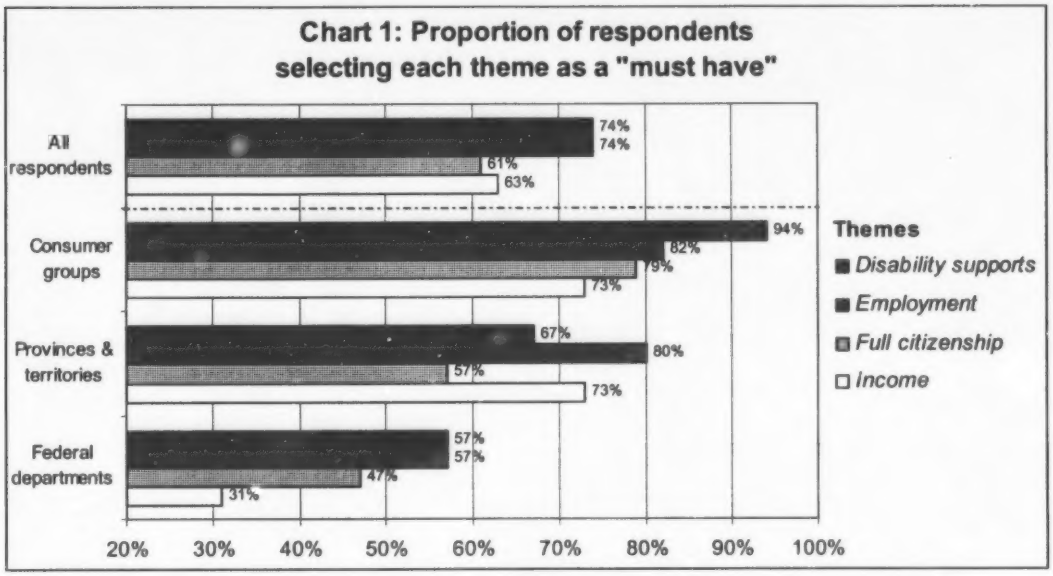
Extent to which data are needed about each theme

Findings showed that each of the four themes was rated positively: information is needed about disability supports, employment, income and full citizenship. However, a closer look at the responses at the extreme positive end of the scale revealed that information about disability supports and employment was more likely to be rated a "must have" compared to income and full citizenship. The following chart shows results by type of organization (Chart 1).

Comparisons among the three largest groups of respondents—consumer, provinces/territories, and federal departments—show that this tendency to identify information about disability supports as highly important is most apparent among the consumer groups. An almost overwhelming proportion of consumer-group respondents (94%) rated disability support information as a 5 (the other 6% rated it a 4). While proportions decreased for employment information, income data, and full citizenship, these three themes were also rated positively by consumer groups. In contrast, a very high proportion of provinces and territories considered employment and income information as a "must have." More federal departments identified having information about disability supports and employment as a "must have" compared to the other two themes. While a smaller proportion of federal respondents regarded full citizenship and

[3] HRDC = 16 questionnaires; other federal departments = 12 questionnaires.

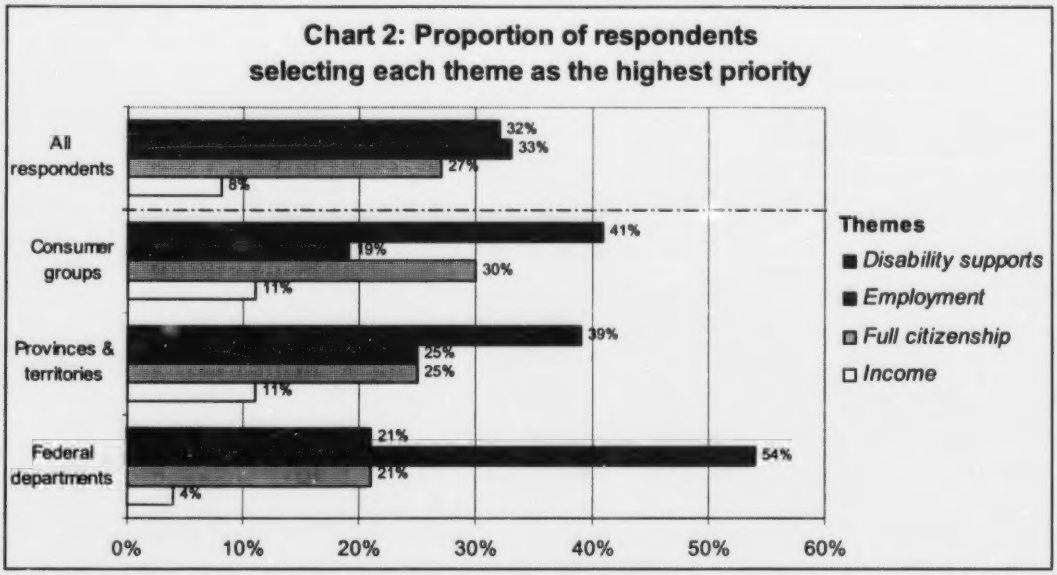
income information as a "must have" these themes had a very positive rating overall among the federal departments.



Prioritizing themes

When asked to prioritize the four themes, about one-third of all respondents identified either employment (33%) or disability supports (32%) as the number one priority, 27% chose full citizenship while only 8% selected income (Chart 2).

Among consumer groups, having information about disability supports was the clear priority with 41% selecting this theme, followed by full citizenship, employment and income. Respondents from the provinces and territories shared this view, with 39% saying disability supports was the most important theme. Employment and full citizenship were selected by one-quarter of provinces and territories, while a small proportion rated income as the most important theme. In contrast, slightly more than half of respondents from federal departments selected employment as their most important theme; disability supports, full citizenship, and income were less of a priority. Among those federal departments rating employment as the number one



priority, two-thirds were respondents from Human Resources Development Canada[4] and one-third were from other federal departments. Among the other remaining federal departments, half selected disability supports as their number one priority; full citizenship was next, followed by income.

The order in which themes were selected by all respondents as their second priority is as follows: disability supports (32%); income (26%); employment (24%); and full citizenship (18%). Having information about disability supports was clearly a high priority, chosen by almost one-third of respondents. As their second highest priority the consumer groups selected full citizenship (37%); provinces and territories chose income (39%); and federal departments focussed on disability supports (39%). (Findings are not shown.)

1.3 Topics

Each theme was divided into a number of topics. Disability supports contained eight topics; employment included thirteen topics; income had four topics; and full citizenship had ten topics for a total of thirty-five topics (listed in Appendix B). Respondents were asked to do two things

[4] There was variation within HRDC among different parts of the department, with some considering disability supports and others, full citizenship, as the most important information needs.

in regard to topics: 1) indicate the extent to which data was needed for each topic and 2) prioritize the topics into the fifteen most important and the ten least important.

Extent to which each topic is needed

Respondents were asked to rate each topic on a five-point scale where 5 means that the information is a "must have" and 1 represents "not needed" (Table 2).

Table 2: Topics most likely to be rated "must have" by at least half of all respondents

Themes	Topics	Rating as "must have"
Disability supports	• Identification of formal and informal disability supports	70%
	• Unmet needs for disability supports	63%
Employment	• Employment barriers	72%
	• Disability supports and employment	64%
	• Education, training, literacy and employment	62%
Income	• Financial resources and the cost of disability	53%
	• Income levels and income mobility	53%
	• Income sources and movement between sources for persons with disabilities	50%
Full citizenship	• Barriers to accessing programs and services and the impact of these barriers	58%
	• Attitudinal barriers to the full participation of persons with disabilities	56%
	• Adequate housing	55%
	• Mobility, movement and transportation	51%

Note: "Must have" is the highest rating on the 5-point scale of data needs.

'Disability supports' contained eight topics. While the overall direction was clearly towards the positive end of the scale, two topics stood out. "The identification of formal and informal disability supports" and "unmet needs for disability supports" were rated a "must have" by over half of all respondents. The remaining six topics were less likely to be considered a 5 but were still regarded very positively[5] by most respondents. The topic which emerged as the least important in terms of information needs was "disability and access to moral support" with only 23% considering it a "must have."

[5] Rated either a 4 or a 5 on the 5-point scale where 5 is a "must have."

The employment theme included thirteen topics. Again all were rated at the positive end of the scale but three topics received the highest levels of endorsement. They are: "employment barriers;" "disability supports and employment;" and "education, training, literacy and employment." These three were considered a "must have" by at least half of all respondents.

Income was divided into four topics and, while the pattern was positive overall, only three of the four were considered by at least half the respondents to be a "must have." Responses were more likely to be distributed across the scale. Around half identified the three following as a "must have": "financial resources and the cost of disability;" "income levels and income mobility;" and "income sources and movement between sources for persons with disabilities." The fourth topic asked about the importance of the effect of an ageing population on disability-related income support and replacement programmes, and only 37% considered it a 5.

Full citizenship had ten topics. Like the income theme, there was less agreement and more variation across the scale. However, responses were still in the positive range but less concentrated. Four topics were considered a "must have" by slightly more than half of the respondents: "barriers to accessing programs and services and the impact of these barriers;" "attitudinal barriers to the full participation of persons with disabilities;" "adequate housing;" and "mobility, movement and transportation." The remaining six topics were not considered as important. Two topics rated the lowest in terms of the need for information: "time use patterns" and "participation in the voluntary sector."

Prioritizing topics

The respondents were asked to select among the 35 topics the fifteen most important and the ten least important topics. The purpose was not to suggest that any of the themes or topics are not important but to let the community make choices about data priorities in order to serve as a guide in the preparation of the new questionnaires.

Top fifteen topics

Respondents were asked to prioritize the topics by selecting the top fifteen and ranking them from the highest to the lowest. There was a great deal of variation in responses with 27 out of the 35 possible topic choices being selected by at least one respondent as their number one priority.

In addition, certain topics selected as the top priority by some respondents were chosen as the lowest priority by others.

The analysis begins by examining the topics chosen as the number one priority. All eight of the disability supports topics were identified as number one priorities. Ten of the thirteen employment topics, three out of four income topics and six of the ten full citizenship topics were included among the number one priorities. For number one priority, 35% of all respondents selected one topic from the employment theme; 33% chose one of the disability supports topics; 26% focused on full citizenship; and 5% identified an income topic.

For the first priority the greatest amount of consensus was around "formal and informal disability supports." The next highest proportion of respondents focused on "movements in and out of the labour force." While the numbers are small again, the tendency to rate information needs about disability supports and employment as highly important emerged. However, "barriers to accessing programs and services and their impacts," which is a full citizenship-theme topic, was also a first priority for a number of respondents (Table 3). Appendix C shows detailed results.

Table 3: Topics most frequently selected as the highest priority

Topics	All	CG	P/T	F
1. Formal and informal disability supports	18%	11%	29%	
2. Movements in and out of the labour force	10%		14%	11%
3. Barriers to accessing programs and services and the impact of barriers	9%	11%	7%	
4. Unmet needs for disability supports	8%	11%	7%	
5. Disability support and employment	7%	11%		11%
6. Employment barriers for persons with disabilities				14%
7. The cost of disability supports		7%		11%
8. Education, training, literacy and employment		11%		
9. Gender, culture, race, ethnicity, disability and citizenship			11%	
10. Technology and employment				11%

Note: 'All' refers to all respondents; CG refers to consumer groups; P/T refers to provincial/territorial governments; and F refers to federal government departments. The latter three columns are the largest groups of respondents.

Lowest ten topics

Opinions differed a great deal about which topics are the least important. When asked to identify the ten topics having the lowest priority, 28 of the 35 topics were identified by at least one person as having the lowest priority. There was no consensus on topic priority: some topics selected as the top priority in the earlier question were chosen as the lowest priority by other respondents. The topics most likely to be selected as the least important are shown in Table 4.

Table 4: Topics most frequently selected as the lowest priority

Topics	All	CG	P/T	F
1. Voluntary and third sector	8%	18%	18%	
2. Time use pattern	9%	14%	7%	7%
3. Tax measures			7%	11%
4. Effect of ageing population		11%		
5. Time of onset and career paths		7%		
6. The world of communication and information			11%	7%
7. Gender, culture or ethnic differences			7%	
8. The effect of cyclical disabilities	6%			7%
9. Youth with disabilities and the transition from school to work		7%		
10. Disability and access to moral support	7%			7%
11. Income				7%
12. Adequate housing				11%

Note: 'All' refers to all respondents; CG refers to consumer groups; P/T refers to provincial/territorial governments; and F refers to federal government departments. The latter three columns are the largest groups of respondents.

For 'all respondents,' four topics emerged as the least important (Table 4). The pattern varied among consumer groups, provinces/territories and the federal government as to which topics were the least important. See Appendix D for a more detailed breakdown.

1.4 Population Coverage and Survey Vehicle

Respondents were asked about the relative importance of having information in HALS 2001 concerning the working-age population, children, seniors and permanent residents of health care institutions. This question served two purposes: to identify data needs of users and to consider whether HALS 2001 is an appropriate vehicle for data collection about persons with disabilities of all ages.

When asked about the relative importance of having information about children, seniors and the institutional population, compared to information on the working-age population, respondents generally tended to rate information about the working-age population as more important (Table 5). However, one-quarter chose information about children (26%); others said the working-age population and children were equally important (16%); and some had no opinion (7%). One-third said having data on seniors was more important or equally important, and 21% said information about those in institutional care was more important or equally important.

Table 5: Proportion of respondents rating importance of information about selected groups, relative to the working-age population

Rates	Children	Seniors	Permanent residents of institutions
More important	26%	20%	12%
Equally important	16%	14%	9%
Less important	52%	60%	74%
No opinion	7%	7%	6%

When asked to specify the importance of obtaining information about certain groups relative to others, some respondents wrote in that both groups were equally important. These responses are included in the analysis.

Table 6: Proportion of respondents rating importance of information about children, relative to the working-age population

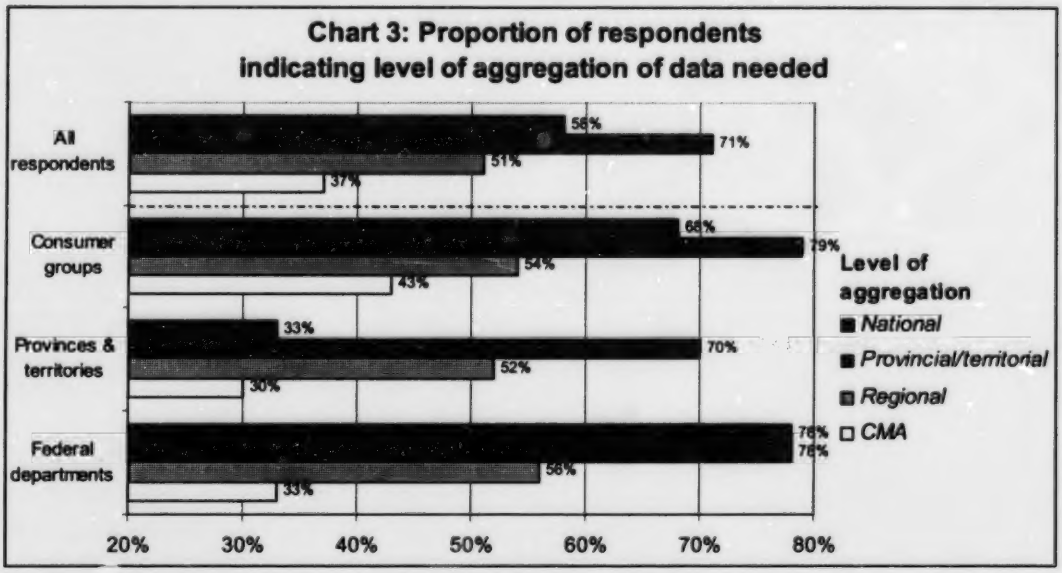
	All respondents	Consumer groups	Provinces and territories	Federal departments
More important	26%	25%	23%	7%
Equally important	16%	29%	7%	7%
Less important	52%	39%	26%	79%
No opinion	7%	7%	4%	7%

Table 6 shows the results for all respondents in the first column and for three largest types of organizations in the next three columns on the question of relative data needs about children versus the working-age population.

As a follow-up to these questions, Statistics Canada was consulted about the feasibility of collecting data on persons with disabilities by means of existing surveys. But due to the small sample size of persons with disabilities in these surveys, it was decided to keep all age groups in HALS.

1.5 Level of Aggregation

We asked respondents at which level of aggregation they needed the data: national, provincial/territorial, regional, or census metropolitan area (CMA). The majority of respondents indicated that provincial/territorial-level data were most likely to be needed; national was next; followed by regional and census metropolitan area (Chart 3).



CMA-level data were needed by a minority of respondents; however, explanations as to why CMA data were needed revealed that it would be used to support programs offered within a local area such as policing, hospitals and libraries and for staffing and funding applications.

1.6 Other Issues

Respondents were invited to provide written comments and to identify any topics necessary to fulfil data needs not covered in the questionnaire. Out of 126 questionnaires, 76 respondents

(60%) provided written feedback. Topics discussed generally fell into four categories: methodological, definitional, content and barriers.

1. Methodological themes included:

- the need for longitudinal data;
- the adequacy of sample size at the provincial level;
- the usefulness of rural/urban breakdowns; and
- retaining comparability between HALS 1991 and HALS 2001.

2. Issues concerning definitions focused on the following three areas:

- the need for new categories to define emerging or new conditions (such as environmental and chemical reactions) and the addition of a category for existing conditions (for example, fetal alcohol syndrome);
- the importance of improving the way non-physical disabilities are defined (specifically, the need to distinguish between the different types such as learning disabilities, learning problems, developmental delay, mental illness and cognitive problems); and
- language-use categories to indicate how many people use sign language and to pinpoint differences among persons who are deaf, hard of hearing and hearing.

3. Content issues encompassed a very broad sweep of topics. They are:

- education and training;
- transitions from school to work;
- general health and well-being;
- family and community;
- child care;
- safety, victimization and access to police services;
- extent of unionization of employed persons with handicaps;
- home care;

- household income and asset/debt levels of persons with disabilities;
- transportation;
- housing; and
- living with a disability in the north.

4. Barriers were mentioned frequently and include:

- problems in accessing programs and services;
- difficulties identifying existing programs and services and who pays for them; and
- attitudinal barriers.

Further suggestions were gained in the next write-in question that asked for additional comments. Issues identified included the following: immigration and the number of refugees with disabilities; comparisons between persons with disabilities and persons without disabilities; the need for household-level data (for this, HALS must be linked back to the census); information problems/ barriers which can occur while travelling; and transitions from childhood to adulthood and into the senior years. One respondent also pointed out that most people think about ramps and automatic doors when disability supports are mentioned. But in fact, it is the "provision of another person skilled in our communication methods," an "intervenor," who makes access to the whole world possible.

Section 2: Consultation Meetings

The consultation meetings took place with community groups representing persons with disabilities in Quebec City, Montreal, Toronto, Ottawa, Winnipeg and Vancouver. There was no protocol and participants were free to raise issues and direct the conversation towards topics of concern to them. These discussions focussed on a broad range of research issues concerning persons with disabilities.

During the meetings HRDC and Statistics Canada were told that the community was extremely pleased about the new survey planned for 2001. Discussions confirmed the need for new and updated information. The most current data are from HALS 1991, which is ten years old.

Rethinking of the 1991 HALS questionnaire was suggested including the addition of new types of data, retaining continuity between the two surveys were suggested. Whether HALS 2001 should be used to produce a general profile or in-depth data about specific topics was discussed. For example, HALS could either focus on the working-age population and use other surveys to study children and seniors, or it could include all age groups.

The consultation noted the lack of information about the effect on the family of having a member with a disability, particularly the consequences for non-standard types of families such as single-parent families. The impact was thought to be potentially quite significant including out-of-pocket financial costs, effects on other children in the family and outcomes for the breadwinner's career. For example, promotions that require re-location might be refused due to potential problems with finding programs and services in the new location.

Problems with definitions were raised. For example, it is important to distinguish between persons who are deaf and those who are hard of hearing. Quebec groups advised caution with the translation of the terminology about disabilities because some terminology is unique to Quebec. There is also a need for standard definitions in all surveys or an algorithm that would allow for easy comparisons between surveys. It was pointed out that newer categories of conditions such as chronic fatigue, HIV/Aids, back injuries, epilepsy should be included in the next survey.

At the same time it was stressed that accurate definitions of the physical or mental condition provide only a partial picture. Also required is the identification of any existing barriers within specific contexts and the type of accommodation needed to overcome those barriers. It was for this reason that the screening questions on HALS 1991 were considered by some respondents to be less useful because they were not linked to barriers in specific settings. It was stressed that the most important thing to know is if the condition limits the individual due to a barrier. If a barrier exists but the individual does not have a support to overcome the barrier, this information could provide a measure of "unmet need."

The desire for more information about educational issues was expressed. The barriers face by youth in the transition from school-to-work need to be examined. The fact that training is more accessible than education for persons with disabilities was pointed out.

A concern was expressed about the confidentiality of data collected. Since all data for HALS 2001 will fall under the *Statistics Canada Act*, confidentiality is protected. This *Act* overrides departmental-level legislation and ensures that data can only be shared with another government department when all identifiable characteristics have been moved from the data and if the individual respondent provides informed consent.

The role of technology was generally seen as both positive and negative. It was widely acknowledged that new technologies are being developed to help people live more independent lives and return to previous activities after severe injuries. The negative side of technology occurs when service delivery is automated and the new technology is not accessible to persons with disabilities (e.g. automatic bank tellers, self-service gas station).

Conclusions

Findings from the consultation process indicate that having data about disability supports, employment, income, and full citizenship is very important. This conclusion is not surprising since the four themes are interrelated and all need to be considered to ensure inclusion. However, more emphasis was placed on having information about disability supports and employment. And there was variation among the different organizations on the relative importance of the four themes. Information about disability supports is found to be the most important for consumer groups. Disability supports include all the goods, technical supports and human services needed on a daily basis to function as a full citizen.

There was overlap between the questionnaire results and the consultation meetings with similar themes emerging. For example, barriers became apparent as issues in both—to identify them and to assess their impact on the individual within specific contexts such as work, school, family and community.

Findings from the consultation questionnaire and the consultation meetings will be used as a guide to content development for the new survey. While the formal part of the consultation process is finished, HRDC continues to have discussions with a variety of groups about research on disability issues.

Appendix A

List of respondents

This list of respondents includes those who responded to the consultation questionnaire and those who wrote letters or submitted general comments.

Federal government departments

Agriculture and Agri-Food Canada
Canadian Human Rights Commission
Canadian Mortgage and Housing Corporation (CMHC)
Canadian Transportation Agency
Citizenship and Immigration Canada (CIC)
Environment Canada
Finance Department
Health Canada
Human Resources Development Canada – National Headquarters (Ottawa)
- Office of Learning Technologies
- CPP Disability
- Income Security Programs
- Office of Disability Issues (ODI)
- Social Policy
- Strategic Policy and Social Policy
- Strategic Planning and External Relations

Human Resources Development Canada – Regional offices
- British Columbia Region
- Saskatchewan Region
- Manitoba Region
- Ontario Region
- Quebec Region
- New Brunswick Region
- Nova Scotia Region
- Prince Edward Island Region
- Newfoundland Region

Industry Canada
Public Service Commission
Revenue Canada
Transport Canada

Provincial/Territorial governments

Government of British Columbia[6]
- Ministry of Social Development & Economic Security
- Ministry of Advanced Education, Training and Technology

[6] The government of British Columbia submitted one response, which represented the views of six departments.

- Ministry of Health
- Ministry for Children and Families
- BC STATS (Ministry of Finance)
- Office of Disability Issues (Ministry of Social Development and Economic Security)

Alberta Human Resources and Employment
Alberta Provincial Board for Persons with Developmental Disabilities
Saskatchewan Municipal Affairs, Culture and Housing
Saskatchewan Provincial Government – Office of Disability Issues
Saskatchewan Public Service Commission
Saskatchewan – Women's Secretariat
Ontario Ministry of Community and Social Services
Institut de la statistique du Québec
Ministère de la Santé et des services sociaux
Ministère de la Solidarité sociale
Ministère de l'emploi et solidarité du Québec
Ministère des Transports du Québec
Office des personnes handicapées du Québec
Secrétariat à la condition féminine
Société d'habitation du Québec
Fredericton Department of Health and Community Services
New Brunswick Statistics Agency
New Brunswick Social Policy Renewal Secretariat
New Brunswick Status of Women
Nova Scotia Department of Community Services
Nova Scotia League for Equal Opportunities
Prince Edward Island Department of Health and Social Services
Newfoundland Department of Health and Community Services
Government of Yukon – Health and Social Services
Yukon – Worker's Compensation Health and Safety Board
Government of Northwest Territories
Northwest Territories Department of Education

Consumer groups

Canadian Aids Society
Canadian Association of the Deaf
Canadian Association of Independent Living Centres
Canadian Council for the Blind
Canadian Hard of Hearing Association
Canadian Injured Workers Alliance
Canadian Mental Health Association
Canadian National Society of the Deaf-Blind
Canadian National Institute for the Blind (CNIB)
Newfoundland and Labrador – Coalition of Persons with Disabilities
Confédération des organismes de personnes handicapées du Québec
Concept Special Business Advisors, Inc.
Council of Canadians with Disabilities

Cowichan Valley Independent Living Resource Centre
Newfoundland – Independent Living Resource Centre
Newfoundland (individual) – Independent Living Resource Centre
Learning Disabilities Association of Canada
National Educational Association of Disabled Students (NEADS)
Neil Squire Foundation
Nova Scotia Disabled Persons Commission
Nova Scotia League for Equal Opportunities (LEO)
Northwest Territories Council for Disabled Persons
One Voice, The Canadian Seniors Network
Prince Edward Island Council of the Disabled
Saskatchewan Institute on Prevention of Handicaps
Thalidomide Victims Association of Canada
War Amputations of Canada
Yukon Council on Disability

Researchers/Academics

Canadian Centre on Disability Studies
Canadian Institute of Child Health
Caledon Institute of Social Policy
Canadian Council on Social Development
Centre for Research & Education in Human Services
City of Calgary, Parks and Recreation – Market Research
Nova Scotia – Faculty of Dalhousie University Health Professions
Hôpital Ste-Justine
Institut de réadaptation en deficience physique de Québec
Roeher Institute
Queen's University – Social Program Evaluation Group
University of British Columbia
University of Western Ontario
University of New Brunswick

Private sector

Canadian Bankers Associations
Chieftain International Inc.
Fédération des travailleurs et traveilleuses du Québec (FTQ)
Global Television Network
Nutter & Nutter Associates Ltd
Petro Canada
Rogers Communications Inc.
West Coast Energy Inc.

Health regions/Municipalities

Calgary Parks and Recreation
Calgary Police Service
Calgary Public Library

City of Calgary, Community & Social Development Department
Winnipeg Hospital Authority
Region of Ottawa-Carleton
Halifax Regional Municipality

Others

Association multi-ethnique pour l'intégration des personnes handicapées du Québec
ARCH - A Legal Resource Centre for Persons with Disabilities
Atomic Energy of Canada (AECL)
Canadian Broadcasting Corporation
Canadian Council on Rehabilitation and Work
Canadian Institute for Health Information
Canadian Mental Health Association
Canadian Rehabilitation Council for the Disabled
Community representatives from HRDC's Persons with Disabilities Advisory Committee
Individual Respondents
Infant Development Program of British Columbia
Link Up Employment Services
National Council of Welfare
New Brunswick Easter Seal March of Dimes
Newfoundland & Labrador AIDS Committee
Nova Scotia Disabled Persons Commission
Premier's Council on the Status of Disabled Persons – Alberta
Premier's Council on the Status of Disabled Persons – New Brunswick
Saskatchewan Housing Corporation
Social Planning Council of Ottawa-Carleton
Tristat Resources
Westcoast Family Support Institute

Appendix B

List of topics by theme

1. Disability supports

a. Identifying Disability Supports (formal and informal)
b. Unmet Needs for Disability Supports
c. Providers of Disability Supports
d. The Cost of Disability Supports
e. Tax Measures and Disability Supports
f. New Technology and Disability Supports
g. Gender, Cultural or Ethnic Differences in Disability Supports
h. Disability and Access to Moral Support
i. Other (Please specify.)

2. Employment

a. Movements In and Out of the Labour Force
b. Discouraged Workers with Disabilities
c. Time of Onset of Disability and Career Paths
d. Disability Supports and Employment
e. Social Support and Employment
f. Education, Training, Literacy and Employment
g. Technology (New and Old) and Employment for Persons with Disabilities
h. Employment Barriers for Persons with Disabilities
i. Working Time Patterns of Persons with Disabilities
j. The Effect of Cyclical Disabilities
k. Self-employment and Persons with Disabilities
l. Youth and Disabilities and the Transition from School to Work
m. Patterns in Job Separation
n. Other (Please specify.)

3. Income

a. Income Sources and Movement Between Sources for Persons with Disabilities
b. Income Levels and Income Mobility of Persons with Disabilities
c. Financial Resources and the Cost of Disability
d. The Effect of an Ageing Population on Disability Related Income Support and Replacement Programmes
e. Other (Please specify.)

4. Full citizenship

a. Barriers to Accessing Generic Programmes and Services, and Impacts of These Barriers
b. Learning, Literacy and Full Citizenship
c. The World of Communications and of Information
d. Technology and Social Inclusion/Exclusion
e. Time Use Patterns and Full Citizenship

f. Gender, Culture, Race, Ethnicity, Disability and Full Citizenship
g. Mobility/Movement and Transport
h. People with Disabilities and the Voluntary/Third Sector
i. Adequate Housing
j. Attitudinal Barriers to the Full Participation of PWD
k. Other (Please specify.)

Appendix C

Table Appendix C: Topics most frequently selected as the highest priority, all respondents

Topics	Priority levels														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Formal and informal disability supports (DS)	17	8	6	4	3	5	1	4	6	3	3	5	4	8	2
2. Movements in and out of the labour force (E)	10	2	3	4	2	2		2	5	3	5	3		4	
3. Barriers to accessing programs and services and the impact of barriers (FC)	9	3	3	3	7	3	3	7	4	6	2	6	5	2	6
4. Unmet needs for disability supports (DS)	8	15	11	4	6	1	3	1	4	3	2	7	5	3	
5. Disability support and employment (E)	7	3	7	8	7	9	10	3	3	3	4	8	2	2	
6. Employment barriers for PWD (E)	5	7	8	3	6	6	4	11	7	4	2	3	3	3	5
7. The cost of disability supports (DS)	5	5	7	8		3	3	1	1	3	5	1	4	2	3
8. Education, training, literacy and employment (E)	4	8	3	6	3	10	10	6	3	5		3	4	1	2
9. Gender, culture, race, ethnicity, disability and citizenship (FC)	4	2	1	1		1	2	1	3	4	3	1	1	5	4
10. Adequate housing (FC)	3	1	2	3	1	3	8	2	3	3	5	2	2	7	6
11. Income sources and movement between sources for PWD (I)	3	1	3	6	3	5	4	4	7	3	5	5	2	2	3
12. Mobility/movement and transportation (FC)	3	3	1		1	1	4	2	4	4	4	7	4	2	6
13. Technology—new & old—and employment for PWD (E)	3	3	3	6	3	4	4	5	2	2	2	2		3	3
14. Working-time patterns of PWD (E)	3	1	3	2	3	1		3	3	3	4		3	2	2
15. Attitudinal barriers to full participation of PWD (FC)	2	5	1	3	4	4	3	2	4	5	4	8	4	4	5
16. Financial resources and the cost of disability (I)	2	4	4	3	12	3	3	4	3	4	7	2	4	5	5
17. Learning, literacy and full citizenship (FC)	2	3	2	1	2	2	2	1	4	4	1	7	3	2	
18. The effect of cyclical disabilities (E)	2		2	1		1	2	3	2		3	3	1	1	2

Table Appendix C (Continued)

19. Disability and access to moral support (DS)	1			2	1	1		2		2	1	3	1	6	5
20. Discouraged workers with disabilities (E)	1	2	3	1	5	1	3		3	2	1	4	8	1	1
21. Gender, cultural or ethnic differences in disability supports (DS)	1	2	2	2	2		3		2	2	1	1	3	2	3
22. Effect of an ageing population on disability-related income support & replacement programmes (I)	1	1	1	3	3	7	1	2	1	2	3	5	4	4	3
23. New technology and disability supports (DS)	1	2	3	5	3	5	1	6		4	1		3	2	
24. Providers of disability supports (DS)	1	4	5	3	3	1	3	4	1	3	4		4	2	5
25. Social support and employment (E)	1	2	2	1	3	3	3	4	4		8	1	6	1	1
26. Tax measures of disability supports (DS)	1		3	1	2	2	3	1	2	1	1		1	2	2
27. Youth with disabilities and the transition from school to work (E)	1	2	3	2	3	3	3	7	3	4	4	6	4	2	2
28. Time of onset of disability and career paths (E)			1		2	2	3	1	1	2	1	1	4	3	3
29. Self-employment and PWD (E)		2		2	1	2	2	4	3	4	1	2	2	3	3
30. Patterns in job separation (E)		1	1	1	2	1		2	3	3	1	2	2	2	
31. Income levels and income mobility of PWD (I)		3	2	4	4	3	7	5	3	3	4	3	6	4	1
32. The world of communications & information (FC)		1	2	3	2	2		1	4	4	3		2	3	7
33. Technology and social inclusion/exclusion (FC)			2	3	2	1	4	4	2	4	5	3	1	3	1
34. Time use patterns and full citizenship (FC)		1	2	2			1	2			1			1	1
35. PWD and the voluntary/third sector (FC)				2	1	1			3	2	2	1	1	2	4
36. Other	4	7	3	1	3	4	2		3	2	5		3	3	4
Total	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*

Note: DS refers to disability supports; E refers to employment; FC refers to full citizenship; I refers to income; PWD refers to persons with disabilities. Totals may not add to 100% due to rounding.

Appendix D

Table Appendix D: Topics most frequently selected as the lowest priority, all respondents

Topics	Priority levels									
	1	2	3	4	5	6	7	8	9	10
1. Time use patterns and full citizenship (FC)	10	9	7	4	8	2	6	3	6	2
2. PWD and the voluntary/third sector (FC)	10	8	5	3	3	9	4	3		5
3. Tax measures of disability supports (DS)	8	6	1	4	3	3	2	5	6	6
4. Disability and access to moral support (DS)	7	5	5	1	3	1	7	5	8	5
5. Adequate housing (FC)	7	3	1	6		2	2	2	1	
6. The world of communications & information (FC)	6	3	3	5	5	2	2	2	5	2
7. Gender, cultural or ethnic differences in disability supports (DS)	6	6	2	1	2	7	3	2	5	4
8. Effect of ageing population on disability related income support & replacement programmes (I)	5	4	5	8	8	2	5	2	2	4
9. Youth with disabilities & the transition from school to work (E)	5	3		3	3		1	2	2	5
10. Income sources and movement between sources for PWD (I)	4	1	2	5		3	3	4	2	2
11. Movements in and out of the labour force (E)	4	2	2		2	4	1	1	1	6
12. Providers of disability supports (DS)	4	1	4		3	1	3	2	3	
13. The effect of cyclical disabilities (E)	4	3	9	12	3	5	6	2	2	7
14. The cost of disability supports (DS)	3	2		2	2			3	1	
15. Self-employment and PWD (E)	2	1	4	7	6	6	3	3	8	7
16. Discouraged workers with disabilities (E)	2	3	1	4	2	2	2	3	6	5
17. Formal and informal disability supports (DS)	2		2	1		1				
18. Patterns in job separation (E)	2	5	3	7	6	7	4	9	5	1
19. Time of onset of disability and career paths (E)	2	5	9	3	6	4	3	3	1	1
20. Learning, literacy and full citizenship (FC)	2	1	1	3	3	5	1	7	2	6

Table Appendix D (Continued)

21. Unmet needs for disability supports (DS)	1	1		1	1	2	1	1		
22. Technology—new & old—and employment PWD (E)	1	3	2	2	2	1	7	1	3	
23. Working-time patterns of PWD (E)	1	5	2	3	6	4	4	5	5	
24. Barriers to accessing programs and services and the impact of barriers (FC)	1	1	3	1	2	1	1	2	2	
25. Technology and social inclusion/exclusion (FC)	1	5	3	6	3	3	2	4	5	2
26. Gender, culture, race, ethnicity, disability and citizenship (FC)	1	2	9	5	2	3	3	3	2	2
27. Attitudinal barriers to full participation of PWD (FC)	1		1	1	2		3	1	2	4
28. New technology and disability supports (DS)	1	6	3	1	3	5	3	3	2	4
29. Disability support and employment (E)			1	2	1		1		1	1
30. Education, training, literacy and employment (E)			1		3	2		1		
31. Employment barriers for PWD (E)			3	1	1			2	1	4
32. Social support and employment (E)		3	2		2	6	3	2	1	1
33. Financial resources and the cost of disability (I)		1	5		1	2		3	6	1
34. Income levels and income mobility of PWD (I)		3	4	1	3	2	6	2	1	6
35. Mobility/movement and transportation (FC)		4		1	2	3	4	2	2	4
36. Other	1						1		1	2
Total	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*	*100*

Note: DS refers to disability supports; E refers to employment; FC refers to full citizenship; I refers to income; PWD refers to persons with disabilities. Totals may not add to 100% due to rounding.